

(c) **METABOLIC DISEASES**

71-519 Screening test; duties; disease management; duties; fees authorized; immunity from liability.

(1) All infants born in the State of Nebraska shall be screened for phenylketonuria, primary hypothyroidism, biotinidase deficiency, galactosemia, hemoglobinopathies, medium-chain acyl co-a dehydrogenase (MCAD) deficiency, and such other metabolic diseases as the Department of Health and Human Services may from time to time specify. Confirmatory tests shall be performed if a presumptive positive result on the screening test is obtained.

(2) The attending physician shall collect or cause to be collected the prescribed blood specimen or specimens and shall submit or cause to be submitted the same to the laboratory designated by the department for the performance of such tests within the period and in the manner prescribed by the department. If a birth is not attended by a physician and the infant does not have a physician, the person registering the birth shall cause such tests to be performed within the period and in the manner prescribed by the department. The laboratory shall within the period and in the manner prescribed by the department perform such tests as are prescribed by the department on the specimen or specimens submitted and report the results of these tests to the physician, if any, the hospital or other birthing facility or other submitter, and the department. The laboratory shall report to the department the results of such tests that are presumptive positive or confirmed positive within the period and in the manner prescribed by the department.

(3) The hospital or other birthing facility shall record the collection of specimens for tests for metabolic diseases and the report of the results of such tests or the absence of such report. For purposes of tracking, monitoring, and referral, the hospital or other birthing facility shall provide from its records, upon the department's request, information about the infant's and mother's location and contact information, and care and treatment of the infant.

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(4)(a) The department shall have authority over the use, retention, and disposal of blood specimens and all related information collected in connection with metabolic disease testing conducted under subsection (1) of this section.

(b) The department shall adopt and promulgate rules and regulations relating to the retention and disposal of such specimens. The rules and regulations shall:

(i) Be consistent with nationally recognized standards for laboratory accreditation and shall comply with all applicable provisions of federal law; (ii) require that the disposal be conducted in the presence of a witness who may be an individual involved in the disposal or any other individual; and (iii) provide for maintenance of a written or electronic record of the disposal, verified by such witness.

(c) The department shall adopt and promulgate rules and regulations relating to the use of such specimens and related information. Such use shall only be made for public health purposes and shall comply with all applicable provisions

of federal law. The department may charge a reasonable fee for evaluating proposals relating to the use of such specimens for public health research and for preparing and supplying specimens for research proposals approved by the department.

(5) The department shall prepare written materials explaining the requirements of this section. The department shall include the following information in the pamphlet:

(a) The nature and purpose of the testing program required under this section, including, but not limited to, a brief description of each condition or disorder listed in subsection (1) of this section;

(b) The purpose and value of the infant's parent, guardian, or person in loco parentis retaining a blood specimen obtained under subsection (6) of this section in a safe place;

(c) The department's procedures for retaining and disposing of blood specimens developed under subsection (4) of this section; and

(d) That the blood specimens taken for purposes of conducting the tests required under subsection (1) of this section may be used for research pursuant to subsection (4) of this section.

(6) In addition to the requirements of subsection (1) of this section, the attending physician or person registering the birth may offer to draw an additional blood specimen from the infant. If such an offer is made, it shall be made to the infant's parent, guardian, or person in loco parentis at the time the blood specimens are drawn for purposes of subsection (1) of this section. If the infant's parent, guardian, or person in loco parentis accepts the offer of an additional blood specimen, the blood specimen shall be preserved in a manner that does not require special storage conditions or techniques, including, but not limited to, lamination. The attending physician or person making the offer shall explain to the parent, guardian, or person in loco parentis at the time the offer is made that the additional blood specimen can be used for future identification purposes and should be kept in a safe place. The attending physician or person making the offer may charge a fee that is not more than the actual cost of obtaining and preserving the additional blood specimen.

(7) The person responsible for causing the tests to be performed under subsection (2) of this section shall inform the parent or legal guardian of the infant of the tests and of the results of the tests and provide, upon any request

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for further information, at least a copy of the written materials prepared under subsection (5) of this section.

(8) Dietary and therapeutic management of the infant with phenylketonuria, primary hypothyroidism, biotinidase deficiency, galactosemia, hemoglobinopathies, MCAD deficiency, or such other metabolic diseases as the department may from time to time specify shall be the responsibility of the child's parent, guardian, or custodian with the aid of a physician selected by such person.

(9) Except for acts of gross negligence or willful or wanton conduct, any

physician, hospital or other birthing facility, laboratory, or other submitter making reports or notifications under sections 71-519 to 71-524 shall be immune from criminal or civil liability of any kind or character based on any statements contained in such reports or notifications.

Source: Laws 1987, LB 385, § 1; Laws 1988, LB 1100, § 99; Laws 1996, LB 1044, § 502; Laws 1998, LB 1073, § 85; Laws 2001, LB 432, § 10; Laws 2002, LB 235, § 1; Laws 2003, LB 119, § 2; Laws 2005, LB 301, § 15; Laws 2007, LB296, § 390.

A neutral law of general applicability need not be supported by a compelling governmental interest even though it may have an incidental effect of burdening religion. *Douglas Cty. v. Anaya*, 269 Neb. 552, 694 N.W.2d 601 (2005).

The assertion of a hybrid rights constitutional claim does not implicate a strict scrutiny review of a statute. A party may not force the government to meet the strict scrutiny standard by merely asserting claims of violations of more than one constitutional right. *Douglas Cty. v. Anaya*, 269 Neb. 552, 694 N.W.2d 601 (2005).

This section does not unlawfully burden a parent's right to freely exercise his or her religion, nor does it unlawfully burden parental rights. The Nebraska Supreme Court determines that using a rational basis test for review, this section is constitutional. *Douglas Cty. v. Anaya*, 269 Neb. 552, 694 N.W.2d 601 (2005).

This section is a neutral law of general applicability. It applies to all babies born in the state and does not discriminate as to which babies must be tested. Its purpose is not directed at religious practices or beliefs. *Douglas Cty. v. Anaya*, 269 Neb. 552, 694 N.W.2d 601 (2005).

71-520 Food supplement and treatment services program; authorized; fees.

The Department of Health and Human Services shall establish a program to provide food supplements and treatment services to individuals suffering from the metabolic diseases set forth in section 71-519. To defray or help defray the costs of any program which may be established by the department under this section, the department may prescribe and assess a scale of fees for the food supplements. The maximum prescribed fee for food supplements shall be no more than the actual cost of providing such supplements. No fees may be charged for formula, and up to two thousand dollars of pharmaceutically manufactured food supplements shall be available to an individual without fees each year.

Source: Laws 1987, LB 385, § 2; Laws 1996, LB 1044, § 503; Laws 1997, LB 610, § 1; Laws 1998, LB 1073, § 86; Laws 2002, LB 235, § 2; Laws 2005, LB 301, § 16; Laws 2007, LB296, § 391.

71-521 Tests and reports; department; duties.

The Department of Health and Human Services shall prescribe the tests, the

test methods and techniques, and such reports and reporting procedures as are necessary to implement sections 71-519 to 71-524.

Source: Laws 1987, LB 385, § 3; Laws 1996, LB 1044, § 504; Laws 2002, LB 235, § 3; Laws 2005, LB 301, § 17; Laws 2007, LB296, § 392.

71-522 Central data registry; department; duties; use of data.

The Department of Health and Human Services shall establish and maintain a central data registry for the collection and storage of reported data concernReissue
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ing metabolic diseases. The department shall use reported data to ensure that all infants born in the State of Nebraska are tested for diseases set forth in section 71-519 or by rule and regulation. The department shall also use reported data to evaluate the quality of the statewide system of newborn screening and develop procedures for quality assurance. Reported data in anonymous or statistical form may be made available by the department for purposes of research.

Source: Laws 1987, LB 385, § 4; Laws 1996, LB 1044, § 505; Laws 1998, LB 1073, § 87; Laws 2002, LB 235, § 4; Laws 2005, LB 301, § 18; Laws 2007, LB296, § 393.

71-523 Departments; powers and duties; adopt rules and regulations; contracting laboratories; requirements; fees.

(1) The Department of Health and Human Services shall provide educational and resource services regarding metabolic diseases to persons affected by sections 71-519 to 71-524 and to the public generally.

(2) The Department of Health and Human Services may apply for, receive, and administer assessed fees and federal or other funds which are available for the purpose of implementing sections 71-519 to 71-524 and may contract for or provide services as may be necessary to implement such sections.

(3) The Department of Health and Human Services shall adopt and promulgate rules and regulations to implement sections 71-519 to 71-524.

(4) The Department of Health and Human Services shall contract, following competitive bidding, with a single laboratory to perform tests, report results, set forth the fee the laboratory will charge for testing, and collect and submit fees pursuant to sections 71-519 to 71-524. The department shall require the contracting laboratory to: (a) Perform testing for all of the diseases pursuant to section 71-519 and in accordance with rules and regulations adopted and promulgated pursuant to this section, (b) maintain certification under the federal Clinical Laboratories Improvement Act of 1967, 42 U.S.C. 263a, as such act and section existed on July 20, 2002, (c) participate in appropriate quality assurance proficiency testing programs offered by the Centers for Disease Control and Prevention of the United States Department of Health and Human Services or other professional laboratory organization, as determined by the Department of Health and Human Services, (d) maintain sufficient contingency arrangements to ensure testing delays of no longer than twenty-four hours in

the event of natural disaster or laboratory equipment failure, and (e) charge to the hospital, other birthing facility, or other submitter the fee provided in the contract for laboratory testing costs and the administration fee specified in subsection (5) of this section. The administration fee collected pursuant to such subsection shall be remitted to the Department of Health and Human Services. (5) The Department of Health and Human Services shall set an administration fee of not more than ten dollars. The department may use the administration fee to pay for the costs of the central data registry, tracking, monitoring, referral, quality assurance, program operation, program development, program evaluation, and treatment services authorized under sections 71-519 to 71-523. The fee shall be collected by the contracting laboratory as provided in subdivision (4)(e) of this section.

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(6) Fees collected for the department pursuant to sections 71-519 to 71-523 shall be remitted to the State Treasurer for credit to the Health and Human Services Cash Fund.

Source: Laws 1987, LB 385, § 5; Laws 1996, LB 1044, § 506; Laws 1997, LB 610, § 2; Laws 1998, LB 1073, § 88; Laws 2002, LB 235, § 5; Laws 2005, LB 301, § 19; Laws 2007, LB296, § 394.

71-524 Enforcement; procedure.

In addition to any other remedies which may be available by law, a civil proceeding to enforce section 71-519 may be brought in the district court of the county where the infant is domiciled or found. The attending physician, the hospital or other birthing facility, the Attorney General, or the county attorney of the county where the infant is domiciled or found may institute such proceedings as are necessary to enforce such section. It shall be the duty of the Attorney General or the county attorney to whom the Department of Health and Human Services reports a violation to cause appropriate proceedings to be initiated without delay. A hearing on any action brought pursuant to this section shall be held within seventy-two hours of the filing of such action, and a decision shall be rendered by the court within twenty-four hours of the close of the hearing.

Source: Laws 1987, LB 385, § 6; Laws 1996, LB 1044, § 507; Laws 2002, LB 235, § 6; Laws 2007, LB296, § 395.